

Hemophilia Treatment Centers



To locate an HTC please visit:
<http://www.cdc.gov/ncbddd/hemophilia/HTC.html>

To reach the National Hemophilia Foundation,
contact: info@hemophilia.org
or 1-800-42-HANDI.



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REFERENCES

¹ Baker JR, Crudder SO, Riske B, Bias V, Forsberg A. *A model for a regional system of care to promote the health and well-being of people with rare chronic genetic disorders.* Am J Public Health. 2005 Nov;95(11):1910-6.

² Grosse SD, Schechter MS, Kulkarni R, Lloyd-Puryear MA, Strickland B, Trevathan E. *Models of comprehensive multidisciplinary care for individuals in the United States with genetic disorders.* Pediatrics 2009;123(1):407-12 (doi:10.1542/peds.2007-2875).

³ Smith PS, Levine PH. *The benefits of comprehensive care of hemophilia: a five-year study of outcomes.* Am J Public Health 1984;74(6):616-7.

⁴ Soucie JM, et al. *Mortality among males with hemophilia: relations with source of medical care.* Blood 2000;96:437-42.

⁵ Soucie JM, Symons J, Evatt B, Brettler D, Huszti H, Linden J, and the Hemophilia Surveillance System Project Investigators. *Home-based factor infusion therapy and hospitalization for bleeding complications among males with hemophilia.* Haemophilia 2001;7:198-206.

Adapted from Region III's *Comprehensive Care and Bleeding Disorder Programs: A Guide for Providers, Patients, and Insurers.*

Hemophilia Treatment Centers



Delivering comprehensive care and improving health for people with bleeding disorders

A Guide for Providers and Insurers





The national network of Comprehensive Hemophilia Diagnostic and Treatment Centers (HTCs) provides expert, team-based health care to people with inherited bleeding disorders and their families. Today, more than 130 HTCs serve patients and families throughout the United States and its territories. They are organized within 12 regional networks funded by the Health Resources Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC). The U.S. HTC network serves as a model for improving health outcomes of people with chronic disease.^{1,2} This successful partnership among health care professionals, consumers, and government agencies offers a health delivery system that provides access to the best possible care and prevention services for people with hemophilia and other inherited bleeding disorders.

Comprehensive Care

Comprehensive care is a systematic, multidisciplinary team approach that provides services in a coordinated, proactive manner to improve the health and quality of life for people with bleeding disorders. Such care includes specialized diagnostics, evaluation, treatment, rehabilitation, and education. The multidisciplinary care team for people with bleeding

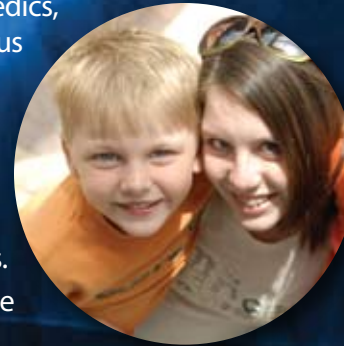
disorders consists of a hematologist, nurse, social worker, and physical therapist. Other specialties represented on a team can include orthopedics, genetics, dentistry, infectious disease, and nutrition. Comprehensive care is provided in the outpatient clinic, during elective or emergency procedures, and during hospitalizations.

The reach of comprehensive care expands into the community. Comprehensive care teams work with schools, health insurance companies, and employers to help affected children stay in school, to maintain patient access to care, and to help adults gain and maintain employment.

Comprehensive care centers provide services to meet all of the needs—physical, psychosocial, and educational—common to patients with bleeding disorders.¹ Care is provided regardless of race, religion, culture, or ability to pay.

A Proven Track Record

HTCs have provided excellence in care since 1975. The comprehensive care model has a proven record of improving health and reducing costs by lowering rates of unemployment, emergency room visits, hospital stays, and illness-related time off from work and school.³ A CDC study showed that the rate of hospital stays for bleeding-related events among patients seen in HTCs was 40% lower than the rates of patients seen in other care facilities.^{4,5} Additionally, patients seen in HTCs are 40% less likely than those seen elsewhere to die of a hemophilia-related complication.⁴



Oversight

In each HTC, a medical director leads the health care team and is accountable to regional leadership. HTCs are monitored through ongoing site visits and evaluations to ensure that treatment and prevention services are provided according to the standards and guidelines of the National Hemophilia Foundation. Regional programs support and further national public health policy goals and objectives and improve the quality of care for children and adults with special health care needs.



Benefits of the HTC Network

HTC providers are experts in diagnosing and treating bleeding disorders. Here are compelling reasons for referral:

Health care quality: HTCs offer high-quality care that includes medical and psychological services and genetic counseling. The HTCs can also connect people with bleeding disorders and their families with needed peer support. Such services are vital to improving health outcomes.

Improved access: HTCs offer extensive outreach and assistance for uninsured and other underserved populations. HTC comprehensive care provides access to the latest treatments, information, research, and clinical trials.

Low-cost medication management: Select non-profit, HTC-based pharmacies provide factor replacement products and other therapies, often at prices much lower than commercial providers. Treatment costs of blood products may be reduced through a federal discount program available at many HTCs.

Family-centered care: HTCs work closely with families to educate and encourage adherence to care plans and treatment regimens.

Diagnosis: Specialized diagnostic services include the availability of coagulation laboratories, personal and family medical histories, viral testing and hepatitis vaccines, and genetic testing and counseling.

Research: HTCs participate in CDC's surveillance program to monitor for bloodborne infections and to collect data to measure health outcomes. In addition, HTCs conduct clinical trials to find new therapies for people with bleeding disorders.

Advocacy and education: HTC staff provide advocacy and education in a number of ways:

- Collaboration with local consumer organizations, the National Hemophilia Foundation, and the Hemophilia Federation of America
- Community outreach to underserved populations
- Patient and community education on state-of-the-art practices in bleeding disorder management
- Financial counseling and advocacy with insurance payers